FACTS

ABOUT DOWN SYNDROME

Named after John Langdon Down, Down syndrome is the most frequently occurring genetic condition. Dr. Down was the first physician to identify the syndrome in 1866.

Down syndrome occurs in one in 800 births, and is present in all races and socio-economic groups.

Down syndrome is a chromosomal disorder caused by an error in cell division that results in the presence of a third chromosome 21 or "Trisomy 21."

This additional genetic material causes the identifying features as well as the cognitive and developmental delays which are common for individuals who have Down syndrome.

THE GOALS OF DSG ARE:
• provide support and resources
• encourage active participation in the community
• foster positive attitudes
• help individuals with Down syndrome reach their full potential

THE DOWN SYNDROME GUILD OF GREATER KANSAS CITY is a 501(c)(3) organization whose mission is to provide support and resources for individuals with Down syndrome, their families and the professionals who serve them. DSG seeks to provide the entire community with information and education to broaden awareness and foster positive attitudes regarding people with Down syndrome. Visit www.kcdsg.org for more information.

History of the Down Syndrome Guild of Greater Kansas City

In 1984, a group of parents whose children had Down syndrome formed the DSG. They envisioned an organized network of resources. This vision has taken the DSG from an emerging grass-roots parent movement to a premier nonprofit organization focused on advancements in education, inclusion and acceptance of people with Down syndrome.

DSG currently serves 37 counties in Kansas and Missouri. We provide support to over 1300 individuals with Down syndrome, their families and the professionals who serve them.

• Formed in 1984 by a group of parents seeking to support one another
• Welcomes approximately 50 new babies with Down Syndrome each year
• Serves more than 1,300 families in the Greater Kansas City area
• Provides administrative and funding support to 15 community groups
• Partners with 22 local hospitals to provide information to new families
• Provides support and assistance to educators in 45 school districts
• Seeks to be the number one resource on Down syndrome in Kansas City
• Hosts one of the largest Down syndrome awareness walks in the nation
• Facilitates social and educational opportunities for throughout the year
• Offers community awareness presentations to breakdown stereotypes
• Envisions a world where all people with Down syndrome are valued

Employment

According to the U.S. Department of Labor report, only 17.1% of people with disabilities are employed compared to 64.6% of the population without disabilities. Of those individuals with disabilities seeking employment, 12.5% have not found employment—compared to 5.9% for everyone else.

• People with disabilities of working age continue to have the highest unemployment rate in the nation compared to those who do not have disabilities.
• People with disabilities make up the only demographic where high unemployment rates are relatively unchanged since 2002.
• In 2014, 33 percent of workers with a disability were employed part time, compared with 18 percent for those with no disability.
• Two-thirds of unemployed people with disabilities said they would like to work but could not find jobs.

For more information about this program visit: www.kcdsg.org/hired.php
MYTHS & TRUTHS

Myth: Down syndrome is a rare genetic disorder
Truth: Down syndrome is the most common genetic condition. One in every 691 births is a child with Down Syndrome. Approximately 5,000 babies are born with Down syndrome each year and there are 250,000 people in the United States living with Down syndrome.

Myth: Down syndrome is hereditary and runs in families
Truth: Most cases of Down syndrome are sporadic, chance events. However, in the instance of translocation, one parent may be identified as a carrier of the translocated chromosome. Down syndrome does not otherwise run in families and a sibling or aunt has no greater chance of conceiving a child with Down syndrome.

Myth: People with Down syndrome have intellectual disabilities
Truth: Most people with Down syndrome have cognitive delays that are mild to moderate. IQ is not an adequate predictor or measure of the functional abilities of people with Down syndrome. People with Down syndrome have great potential if given opportunities.

Myth: People with Down syndrome are placed in and benefit from segregated special education programs
Truth: Children with Down syndrome are included in regular academic classrooms across the country. Students may be integrated into specific courses or fully included in the regular classroom for all subjects. The degree of inclusion is based on the ability of the individual, but the goal is full inclusion.

Myth: People with Down syndrome have extra cognitive delays
Truth: People with Down syndrome do not have extra cognitive delays.

Myth: Adults with Down syndrome cannot form interpersonal relationships, or marry
Truth: People with Down syndrome are quite capable of forming long term loving relationships at all stages of their development. Many people with Down syndrome will date and some will get married and live with support from their families or provider organizations.

Myth: Parents who receive a prenatal diagnosis of Down syndrome will often choose to terminate their pregnancies
Truth: While some parents choose to terminate a pregnancy upon diagnosis of Down syndrome, many keep their babies. Many parents also consider adoption as an option. There are 200 families registered who have indicated they would like to adopt a child with Down syndrome.

Myth: All people with Down syndrome develop Alzheimer’s disease
Truth: Approximately twenty-five percent of adults with Down syndrome over the age of 35 show clinical signs and symptoms of Alzheimer-type dementia, the percentage increases with age. The incidence of Alzheimer’s disease in the Down syndrome population is three to five times greater than in the general population, which is 5-10 percent in people over the age of 65.

Myth: Most children with Down syndrome are born to older parents
Truth: Eighty percent of children born with Down syndrome are born to women younger than 35 due to higher fertility rates. However, Down syndrome has no link between the incidence of having a child with Down syndrome and maternal age.

FACTS ABOUT DOWN SYNDROME

- 1 in every 800 births will be a child with Down syndrome.
- There are 250,000 individuals with Down syndrome living in the United States.
- 6,000 babies are born with Down syndrome each year.
- The average lifespan of a person born with Down syndrome today is 55-60.
- 45% of individuals with Down syndrome will have a congenital heart condition.
- All people with Down syndrome will experience some level of cognitive delay.
- Individuals with Down syndrome benefit from early intervention services which include speech, occupational and physical therapy.

Prenatal screening and diagnostic tests may detect Down syndrome in the womb. A karyotype test is typically done shortly after birth to provide parents a definitive diagnosis. Chromosome variations occur among people with Down syndrome.

**Myth:** People with Down syndrome who have an extra #21 chromosome in every cell of their body have the variation known as Trisomy 21.

**Misnomer:** People with Down syndrome who have an extra #21 chromosome attached to another chromosome have the variation known as Translocation and a parent may be a carrier of a balanced translocation.

**Mosaicism**

People with Down syndrome who have an extra #21 chromosome in some cells, but not in others have the variation known as mosaic Down syndrome.

**Trisomy 21**
People with Down syndrome who have an extra #21 chromosome in every cell of their body have the variation known as Trisomy 21.

**Translocation**
People with Down syndrome who have an extra #21 chromosome attached to another chromosome have the variation known as Translocation and a parent may be a carrier of a balanced translocation.

100% Of Down Syndrome Individuals Have Down Syndrome

October may be Down Syndrome Awareness Month, but I am worth celebrating all year long!

The words we use have the power to help or hurt. It’s imperative that people who support individuals with Down syndrome use People First Language at all times. People with Down syndrome have the same rights as everyone else and should be treated with respect.

Spelling
The correct spelling is Down Syndrome. There is no apostrophe ‘s’ following Down. Dr. John Langdon Down provided the first formal description of the syndrome, but he did not have Down syndrome and therefore no possessive is used. Also, the ‘y’ in syndrome is not capitalized.

People First Language
Individually with Down syndrome are people first. The emphasis should be on the individual, not the disability. For example: a baby, child or adult with Down syndrome, not ‘Down syndrome child’ or ‘Down’s baby. If mentioning a person has Down syndrome is not relevant to the discussion, why bring it up at all?

Generalizations
Avoid generalizations about people with Down syndrome such as they are always loving, always smiling, or perpetually happy. People with Down syndrome are not all alike.

The abilities and characteristics among individuals with Down syndrome can be best described as the same for those in the general population.

Judgment
Please avoid judgmental terminology. A person with Down syndrome does not “suffer from”, and is not “a victim of” or “afflicted with” Down syndrome. Down syndrome is not a disease and these references only diminish a person’s dignity.

Alternate suggestions for describing the syndrome include “living with Down syndrome” or “he/she has a medical condition known as Down syndrome.

A Developmental Disability
Down syndrome is a chromosomal disorder that is present at conception. Using the term ‘birth defect’ or ‘disability’ in relation to Down syndrome is incorrect. There is no known cause or cure for Down syndrome so these terms are inaccurate.

People with Down syndrome usually experience mild to moderate physical and intellectual delays. When referring to a person with Down syndrome, the terms mental retardation and mongoloid are considered outdated, offensive and should be avoided.